

AMERICAN BRAIN TUMOR ASSOCIATION

Pituitary Tumors



American
Brain Tumor
Association®

Providing and pursuing answers®

ACKNOWLEDGEMENTS

ABOUT THE AMERICAN BRAIN TUMOR ASSOCIATION

Founded in 1973, the American Brain Tumor Association (ABTA) was the first national nonprofit organization dedicated solely to brain tumor research. The ABTA has since expanded our mission and now provides comprehensive resources to support the complex needs of brain tumor patients and caregivers, across all ages and tumor types, as well as the critical funding of research in the pursuit of breakthroughs in brain tumor diagnoses, treatments and care.

To learn more, visit [abta.org](https://www.abta.org).

The ABTA gratefully acknowledges the following individuals for their review of this brochure edition:

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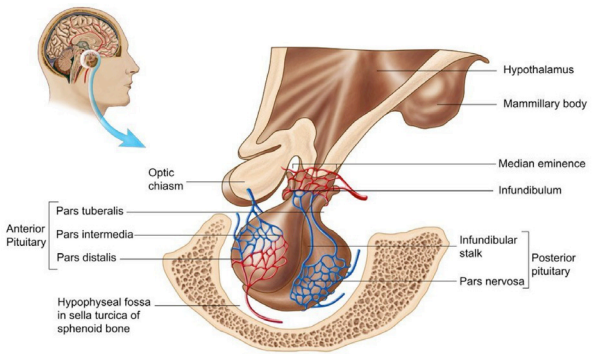
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Pituitary Tumors

INTRODUCTION

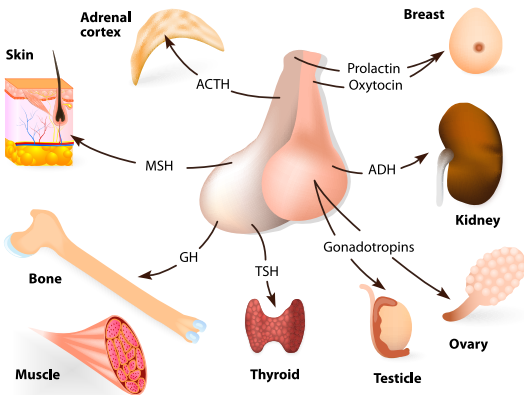
The pituitary gland is a bean-sized organ located at the base of the brain, just behind the bridge of the nose, in a bony pouch called the “sella turcica.” There are several types of masses that can affect the pituitary gland, including cysts, abscesses, cancer metastases, and vascular abnormalities. **The most common type of pituitary mass is pituitary adenoma** (“adeno” means gland and “oma” means tumor), which is considered a primary brain tumor. In this brochure, the word “tumor” refers primarily to pituitary adenomas.

Most pituitary adenomas develop in the front two-thirds of the pituitary gland. This area is called the adenohypophysis or the anterior pituitary gland. Pituitary tumors rarely develop in the rear one-third of the pituitary gland called the neurohypophysis or the posterior pituitary gland. **Pituitary tumors are almost always benign (non-cancerous) and most are successfully treatable.**



The pituitary itself is known as the “master gland” because it helps to control the secretion of hormones from a number of other glands and organs in the body. The pituitary gland releases hormones into the blood stream that are carried to distant glands (i.e., thyroid, adrenals, testes and ovaries) that, in turn, release other hormones which feed back to the brain and the pituitary through the bloodstream. A stem-like stalk connects the pituitary gland to the hypothalamus. The hypothalamus signals the pituitary gland to secrete more hormones or slow down hormone production, depending on the needs of the body.

ENDOCRINE GLANDS (Target Organs)



Studies of the general population reveal that abnormalities including small tumors and benign cysts within the pituitary are quite common. It is estimated

that 20–25% of the general population may have small, asymptomatic pituitary tumors or cysts. It appears that 10% of the general population will have an abnormality big enough to see on magnetic resonance imaging (MRI). These abnormalities most often do not cause symptoms and generally do not require medical or surgical therapy.

Some tumors can be treated effectively with medications while others require surgery and/or radiation therapy. Because the pituitary gland is important in the control of other hormone glands in the body, treating a pituitary tumor requires a coordinated, multi-disciplinary healthcare approach, support and follow-up.

INCIDENCE

About 13,770 pituitary gland tumors are diagnosed annually in the U.S., accounting for about 17% of all primary tumors in the central nervous system (CNS), making them the second most common primary CNS tumor in adults after meningiomas. Very few pituitary gland tumors will be malignant (cancerous).

Pituitary adenomas can be found in every age group, but the incidence is highest in those age 40-64. The incidence rate is higher in African Americans and Hispanics, than Caucasians. Women are diagnosed with pituitary tumors slightly more often than men. This may be a result of a tumor's interference with the menstrual cycle, which sometimes makes symptoms more obvious.

Pituitary adenomas are the most common primary brain tumor diagnosed in adolescents age 15-19 (31.8%).

CAUSES

Pituitary tumors, similar to tumors located elsewhere in the body, are presumed to develop from one abnormal cell that multiplies into many secondary cells, eventually forming a tumor. Stimulating factors from the hypothalamus also may contribute to tumor occurrence and growth. If your doctor concludes that you have a pituitary tumor, the next step is determining the actual “type” of pituitary tumor.

TYPES OF TUMORS

Pituitary tumors may be classified and named by:

- The hormones they secrete, if any
- Their size
- The appearance of the tumor cells under a microscope and the molecular makeup

HORMONES

Some pituitary tumors secrete excessive amounts of a particular hormone. These are known by several names including **functioning adenomas**, **hormonally active adenomas**, and **secretory adenomas**.

Functioning or secreting pituitary tumors may cause the pituitary gland to ignore the signals from the hypothalamus, allowing the pituitary gland to independently secrete excessive amounts of hormones such as prolactin (PRL), growth hormone (GH), adrenocorticotrophic hormone (ACTH), or thyroid-stimulating hormone (TSH). Pituitary tumors that secrete ACTH cause Cushing’s disease, and those that secrete GH cause acromegaly. Sometimes these tumors secrete more than one type of hormone.

Nonfunctioning adenomas (NFAs) do not oversecrete any active hormone at all and may even cause a slow down or a stoppage in hormone production (a

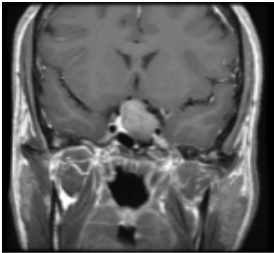
condition called hypopituitarism). Other names for these nonsecreting tumors include “hormonally inactive,” “non-secretory adenomas,” or “silent adenomas.”

SIZE

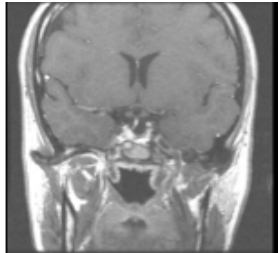
Pituitary tumors also are classified by their size. Tumors appearing to be 10 mm or smaller (about 3/8” of an inch) in diameter on an MRI scan are called **microadenomas**. Those larger than 10 mm are called **macroadenomas**.

MRI SCANS

Preoperative



Postoperative



MRI of a Pituitary Macroadenoma (Pre and Postoperative)

MICROSCOPIC APPEARANCE

If the tumor is surgically removed, it will be examined by a pathologist—a doctor trained to diagnose tumors based on their appearance under a microscope and the molecular makeup of the tumor. The pathologist will examine a sample of the tumor tissue and provide a pathology report to your doctor. A pathology report describes the hormone content, structure, and the cells that gave rise to the tumor. It usually takes about a week for your doctor to receive the surgical pathology report. All of this information is then used to determine tumor type, form a treatment plan and predict the possible future activity of the tumor. Pituitary tumors are almost always benign (non-cancerous), but they can recur after treatment.

SYMPTOMS

Since almost 70% of pituitary tumors are **functioning**, or secreting tumors, the most common symptoms are related to excess hormone production. Lack of menstrual periods (amenorrhea), production of breast milk without pregnancy (galactorrhea), excessive growth (acromegaly or gigantism), Cushing's syndrome, and/or a hyperactive thyroid may be clues to the presence of a tumor in the gland. Headache, vision changes, sleep and eating disorders, and excessive thirst and urination (diabetes insipidus) may also be noted.

Non-functioning tumors usually have symptoms of headache, visual loss, and fatigue (lack of energy). Fatigue may be caused by hypopituitarism. This results from compression of the normal pituitary gland by the tumor.

DIAGNOSIS

If your doctor suspects you have a tumor, several tests are available that can help determine the diagnosis. Special blood tests can measure your hormone levels and whether the pituitary gland is the source of any excess hormone. Different types of hormones play different roles within the body.

Following a neurological and often a vision test as well as endocrine screening (blood hormone levels), an MRI scan with contrast dye is used to obtain images of the pituitary gland, the sella, and the area around it.

In some circumstances, scans of the chest or abdomen may be necessary to verify that the hormone imbalances are caused by the pituitary gland. An ophthalmologist—a doctor specializing in visual problems—may examine your eyes if the tumor affects your eyesight and impairs peripheral vision.

Hormone	Responsible for ...	Normal Blood Levels in Adults
ACTH adrenocorticotrophic hormone	Controls the production of cortisol – a natural steroid needed to control blood pressure, sugar and salt levels	9 to 52 ng/ml
GH growth hormone	Controls bone growth; height; body proportion in the extremities and jaw	0 to 3 ng/ml
PRL prolactin	Controls milk production in women, impacts sex drive and sperm counts in men	Males and non-pregnant women: 0 to 20 ng/ml In pregnancy: 10 to 300 ng/ml
TSH thyroid-stimulating hormone	Controls thyroid functions such as metabolism, heart rate and appetite	0.5 to 5.7 mIU/L

Sometimes, pituitary tumors are found “incidentally.” This usually means the tumor was seen on an MRI scan ordered for another, unassociated medical reason such as a sports-related accident, head injury, sinus disease, and neck pain. These symptomless tumors require careful evaluation, but may not always need immediate treatment.

SPECIFIC TYPES OF PITUITARY TUMORS

PROLACTINOMAS OR PROLACTIN-PRODUCING ADENOMAS

Prolactinomas represent about 30-40% of all pituitary adenomas, making them the most common subtype. Prolactinomas are most often found in women of childbearing age. In men, prolactinomas are more frequent in the fourth and fifth decades of life. About half of these tumors are microadenomas, which are small tumors.

In women, high prolactin levels may stop menstruation (amenorrhea) or lead to unexpected production of breast milk (galactorrhea), and loss of libido. In men, prolactin-secreting tumors may cause a decreased sex drive and impotence. Men also tend to develop larger tumors which may cause headaches or vision problems. Prolactinomas can often be treated medically and seldom require surgery.

GROWTH HORMONE-PRODUCING ADENOMAS (ACROMEGALY AND GIGANTISM)

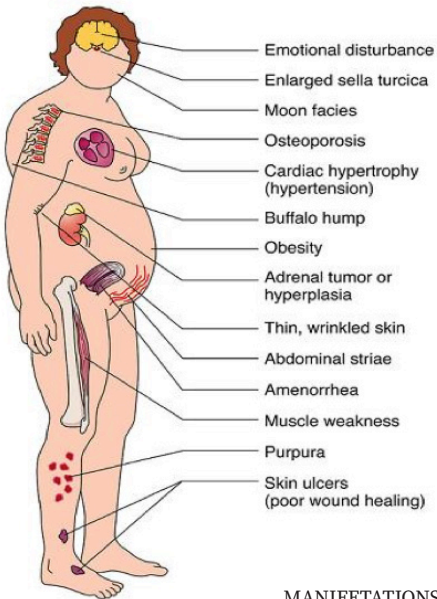
These tumors represent about 20% of pituitary adenomas. Growth hormone-producing tumors are more common in men than in women. Often macroadenomas, these tumors may extend toward the cavernous sinus, an area of the brain located next to the pituitary. Mixed prolactin and growth hormone-secreting tumors are not uncommon.

Growth hormone-secreting tumors may cause gigantism in children and adolescents. In adults who have reached their full height, their hands, feet, and lower jaw become enlarged. This is called acromegaly. Excessive growth hormone can aggravate other medical conditions such as diabetes, hypertension and heart disease.

ACTH-PRODUCING ADENOMAS AND CUSHING'S DISEASE

These tumors represent about 16% of pituitary adenomas. They are much more common in women than in men. ACTH (adrenocorticotrophic hormone) stimulates the adrenal gland to make and secrete glucocorticoids, which are natural steroids. Excess glucocorticoids cause Cushing's disease. Some of the symptoms of Cushing's disease are a moon-shaped face, excess hair growth on the body, bruising, menstrual irregularities, and high blood pressure. Cushing's disease can be a severe and life-threatening condition if

not treated successfully and if hormone levels remain elevated.



MANIFESTATIONS OF CUSHING'S DISEASE

PITUITARY CARCINOMA

Pituitary carcinomas are very rare, representing less than 1% of all pituitary adenomas. This type of tumor begins in the pituitary gland and then metastasizes, or spreads, within the brain or outside the central nervous system. These tumors are generally macroadenomas, which are resistant to therapy, recur locally, and ultimately metastasize to the spinal canal or other organs of the body. The majority of pituitary carcinomas are functioning tumors, secreting prolactin or ACTH.

OTHER HYPERSECRETING PITUITARY ADENOMAS

This group represents less than 1% of pituitary adenomas. Some of these tumors excrete increased amounts of thyrotropin (thyroid-stimulating hormone). Others may secrete follicle-stimulating hormone/luteinizing hormone,

which controls the ovaries and testes, or alpha subunit, an inactive glycoprotein hormone.

NON-SECRETING PITUITARY ADENOMAS

Also called non-functioning pituitary tumors, these represent about 25% of pituitary adenomas. Null cell adenomas, oncocytomas, silent corticotroph adenomas, silent gonadotroph and thyrotroph adenomas fall into this group. These tumors grow slowly and generally cause minimal symptoms. They may be sizable before their presence is suspected. When they expand outside the sella turcica, they may press on the nearby optic nerves causing vision loss and headache. Such tumors also can compress the pituitary gland itself so it cannot produce and deliver its normal output of hormones. Called hypopituitarism, this symptom is associated with general weakness and fatigue, a pale complexion, loss of sexual function, and apathy.

TREATMENT

Treatment of a pituitary adenoma depends on the hormonal activity of the tumor, its size and location, and the age and overall health of the individual.

The goals of treatment may be to remove the tumor, improve vision, reduce or control tumor size, and/or to re-balance hormone levels.

DRUG THERAPY

There are several drugs to treat pituitary adenoma symptoms. The drug chosen will depend on the hormone functions of the tumor.

Dopamine agonists, such as bromocriptine or cabergoline, are used to control the production of prolactin. These drugs can reduce tumor size and normalize the amount of prolactin made by the pituitary gland. Most people with prolactin-secreting tumors require long-term drug therapy to control the size of their tumor; generally, if the medication

is stopped prolactin levels begin to increase. In a small percentage of people with very small tumors, treatment may be stopped after some years to see if the tumor re-grows. Dopamine agonists, also can be given to treat some growth hormone-secreting tumors, but their effect is primarily relief of symptoms rather than a reduction of hormone levels to normal.

Those with very high prolactin levels may find that drug therapy decreases their hormone levels but does not relieve all of their symptoms. In these situations, the drug successfully lowers the prolactin level but the level may still be higher than “normal,” and may still cause symptoms.

Somatostatin analogues such as octreotide (Sandostatin or Sandostatin LAR, or Lanreotide) can reduce growth hormone levels and relieve the associated symptoms. These drugs also may be used to control the production of thyroid-stimulating hormone in thyrotropic tumors.

A growth hormone receptor antagonist drug called pegvisomant (Somavert) can be effective in normalizing a protein called IGF-1, found at elevated levels in people with acromegaly. The drug may be used when other approaches such as surgery, radiation, or somatostatin analogues are not successful.

Ketoconazole (Nizoral) is used to treat ACTH-secreting tumors that cause Cushing’s disease. This drug lowers cortisol (natural steroid) production, but generally does not reduce the size of the tumor or inhibit its activity, and is not suitable for long-term treatment. Pasireotide and mifepristone have been used for treatment of Cushing’s disease, but have specific indications, some side effects, and are not able to cure the tumor.

Newer drugs are being considered in research studies called clinical trials. Clinical trials offer individuals the chance to use new or experimental tests and treatments (meaning they have not yet been proven) before they are

available to the public. However, there is the risk that the treatment being studied may not work or comes with severe side effects.

Individuals who want to join a clinical trial volunteer and must meet certain rules called eligibility criteria, such as having a specific type of tumor or not having been treated with a certain therapy. Talk to your doctor to see if a clinical trial is a good option for you.

To learn more, read the ABTA's Clinical Trials brochure.

SURGERY

If your doctor recommends surgery, the goal will be to remove as much tumor as possible. A transsphenoidal approach—meaning “through the sphenoid sinus”—is the most common. During this surgery, extremely small instruments, microscopes, and endoscopes are used to remove the tumor from within the nose (endonasal) or under the lip and above the teeth (sublabial). Less often, a craniotomy may be done, during which a portion of the skull bone is temporarily removed to gain access to the pituitary gland. Some surgeons use endoscopes (a long, thin, tube-like instrument) through the nostrils (endonasal approach) to reach the tumor.

Your neurosurgeon will speak with you about the surgery planned for your tumor, the risks and benefits of the procedure, and your follow-up care.

To learn more, read the ABTA's Surgery brochure.

RADIATION THERAPY AND RADIOSURGERY

Radiation therapy or radiosurgery are sometimes used as adjuvant (secondary) treatments for pituitary tumors. They may be given in place of surgery or in addition to surgery and/or drug therapy.

Radiation therapy may be used to treat aggressive tumors or those that have re-grown. The goal of

radiation therapy for pituitary tumors is to reduce or control tumor size; however, it may take several months or longer before the effects of this treatment cause a change in your hormone levels or tumor size.

There are several different types of radiation therapy; if needed, your doctor will suggest which may be best for your tumor. **Conventional fractionated external beam radiation** is “standard” radiation usually given 5 days a week for 5 or 6 weeks.

Stereotactic radiosurgery (SRS) is another type of radiation that allows precisely focused, high dose radiation beams to be delivered to a small, localized area of the brain. There are different technologies used to deliver SRS. Although the equipment or method varies, the goal is the same. SRS can be delivered using customized linear accelerators or approaches such as Gamma Knife®, CyberKnife®, or proton-based delivery systems.

Intensity-modulated radiation therapy (IMRT), also known as conformal photon radiation, shapes radiation beams to the contours of the tumor.

To learn more, read the ABTA’s **Conventional Radiation Therapy, Stereotactic Radiosurgery, and Proton Therapy brochures**.

FOLLOW-UP

Once you recover from surgery or radiation therapy, or begin medical treatment, your doctors will determine a schedule for follow-up MRI scans and endocrine testing. These are used to monitor the effectiveness of therapy, assure normal hormonal balance, and watch for possible tumor re-growth.

Many people with pituitary tumors are followed regularly by an endocrinologist. The endocrinologist will monitor

your hormone blood levels, outline a treatment plan and make drug adjustments when needed. The endocrinologist and the advanced practice nurses on both the endocrinology and neurosurgery teams become active members of your healthcare team, working closely with your internist or primary care physician.

Although pituitary tumors are almost always non-malignant (not cancer), they can recur, and therefore periodic follow-up MRI scans are necessary. Your doctor will tell you how often those scans should be done. If you do not know when your next MRI should be scheduled, call your doctor's office to ask.

PROGNOSIS

The 5-year survival rate tells you what percent of people live at least 5 years after the tumor is found. Percent means how many out of 100. The 5-year survival rate for people with a pituitary tumor is 97%. Survival rates depend on the type of tumor, a person's age, and other factors.

AMERICAN BRAIN TUMOR ASSOCIATION INFORMATION, RESOURCES AND SUPPORT

Educational brochures are available on our website or can be requested in hard copy format for free by calling the ABTA. Most brochures are available in Spanish, with exceptions marked with an asterisk.

GENERAL INFORMATION

About Brain Tumors: A Primer for Patients and Caregivers

Brain Tumor Dictionary*

Brain Tumors Handbook for the Newly Diagnosed*

Caregiver Handbook*

TUMOR TYPES

Ependymoma

Glioblastoma and Anaplastic Astrocytoma

Medulloblastoma

Meningioma

Metastatic Brain Tumors

Oligodendroglioma and Oligoastrocytoma

Pituitary Tumors

TREATMENT

Chemotherapy

Clinical Trials

Conventional Radiation Therapy

Proton Therapy

Stereotactic Radiosurgery*

Steroids

Surgery

AMERICAN BRAIN TUMOR ASSOCIATION INFORMATION, RESOURCES AND SUPPORT

INFORMATION

ABTA WEBSITE | [ABTA.ORG](https://abta.org)

Offers more than 200 pages of information, programs, support services and resources, including: brain tumor treatment center and support group locators, caregiver resources, research updates and tumor type and treatment information across all ages and tumor types.

EDUCATION & SUPPORT

- **ABTA Educational Meetings & Webinars**
In-person and virtual educational meetings led by nationally-recognized medical professionals.
- **ABTA Patient & Caregiver Mentor Support Program**
Connect with a trained patient or caregiver mentor to help navigate a brain tumor diagnosis.
- **ABTA Connections Community**
An online support and discussion community of more than 25,000 members.
- **ABTA CareLine**
For personalized information and resources, call 800-886-ABTA (2282) or email info@abta.org to connect with a CareLine staff member.

GET INVOLVED

- Join an ABTA fundraising event.
- Donate by visiting abta.org/donate.

CONTACT THE ABTA

CareLine: 800-886-ABTA (2282)

Email: info@abta.org

Website: abta.org

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